

# **TESTIMONY ON BEHALF OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH SUBMITTED BY KATHRYN G. SCHUBERT, PRESIDENT & CEO**

## **Prepared for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies**

On behalf of the Society for Women's Health Research (SWHR), I am pleased to submit testimony to the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies. We will highlight important work related to women's health being conducted at the U.S. Department of Health and Human Services (HHS) for FY2021. With that in mind, SWHR urges Congress to ensure the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA) and Agency for Healthcare Research and Quality (AHRQ) are adequately funded in FY2021.

We specifically urge the Committee to support a total of \$44.7 billion for the NIH, including proportional increases to fund the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and Office of Research on Women's Health (ORWH). We support at least \$8.3 billion in funding for the CDC; \$8.8 billion for HRSA, including at least \$715 million for the Title V Maternal and Child Health (MCH) Services Block Grant; and \$471 million for AHRQ. We encourage continued, sustained, broad support for HHS and programs relevant to women's health and women's health research.

Founded in 1990, SWHR is the thought leader in promoting research on biological sex differences in disease and improving women's health through science, policy, and education. An appropriately funded, robust federal research agenda that is committed to furthering women's health research is critical for the U.S. to address gaps in knowledge and achieve equity in healthcare for women.

### **NATIONAL INSTITUTES OF HEALTH (NIH)**

The NIH is America's premier medical research agency and the largest source of funding for biomedical and behavioral research in the world. As such, its public health mission is vital to promote the overall health and well-being of Americans by fostering creative discoveries and innovative research, training and supporting researchers to ensure continued scientific progress, and expanding the scientific and medical knowledge base.

Multiple initiatives within the NIH are aimed at improving the health of women. The agency released its Trans-NIH Strategic Plan for Women's Health Research in April 2019, which laid out broad agency goals to complement its more targeted women's health programs. The NIH's emphasis on improving standard research methodologies to better address sex and gender and funding relevant women's health research makes continued strong support of this agency fundamental to supporting women's health.

### **Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**

Housed within the NIH, the NICHD has achieved extraordinary feats in research on women's health throughout the lifecycle. The NICHD conducts critical and timely studies that support the health of women and children – such as the recently launched study analyzing the effects of the COVID-19 pandemic on pregnancy and delivery nationwide. It is only with adequate resources

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that the NICHD can build upon new and existing initiatives to address knowledge gaps and identify solutions to benefit women, children, and families throughout the U.S. Several of these initiatives are detailed below.

***Reproductive Sciences:*** The NICHD's reproductive biology research is vital in improving treatment options for serious gynecologic conditions. Research on many of these conditions is broadly underfunded in proportion to their significant burden on millions of women. For example, more than 11% of reproductive-aged women are living with endometriosis, and more than 80% of African American women and almost 70% of white women will develop uterine fibroids at some point in their lifetime. Despite the prevalence of these diseases and their potentially severe effects on women, their families, and society, a clear understanding of the basic biology behind these conditions is lacking, resulting in delayed diagnosis and limited treatment options. Given the history of limited funding allocated to research on these conditions, it is imperative that the NICHD receive robust funding to continue and expand upon this essential work.

***Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC):*** The NICHD is leading the field in supporting inclusion of pregnant and lactating women in clinical trials. Pregnant women historically have been excluded from research — even in studies that would advance knowledge of medical conditions and treatments in pregnancy. The PRGLAC task force is now in the second phase of its efforts to develop a strategy to implement 15 recommendations outlined in its mandated report to Congress and HHS. The NICHD must have sufficient resources for PRGLAC to continue its important work in this area.

***PregSource®:*** The NICHD's PregSource initiative allows pregnant women to track health data from gestation to early infancy and access evidence-based information about normal and abnormal pregnancy experiences. This program encourages researchers to use aggregated data and recruit pregnant and postpartum women in clinical trials. It is making important headway in eliminating knowledge gaps and imbalances in care for these understudied patient populations.

***Maternal Mortality:*** The NICHD's Pregnancy and Perinatology Branch plays a pivotal role in supporting research to improve the health of women before, during, and after pregnancy. Its work is central in continuing to reduce the number of preterm births and pregnancy and delivery complications, and in ensuring the long-term health of mothers and their children. Approximately 10% of births in the US are preterm, and rates are much higher in some minority populations. The 2018 US maternal mortality rate was 17.4 deaths for every 100,000 live births — meaning the US is faring much worse than comparatively wealthy countries. Research conducted in these areas by the NICHD and other agencies will be crucial in limiting the number of pregnancy-related complications and deaths in the US.

### **Office of Research on Women's Health (ORWH)**

As the NIH focal point for coordinating women's health research, the ORWH ensures women are appropriately represented in biomedical and behavioral research supported by the NIH. SWHR has long supported the idea that studying, analyzing, and reporting on sex differences should be standard practice across all research. It is well-known that sex differences exist at all

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levels: cellular, molecular, and systems. Furthermore, it is understood that these differences affect research outcomes in a variety of significant ways.

In 2015, the NIH announced a policy (NOT-OD-15-102) to factor sex as a biological variable (SABV) into research designs, analyses, and reporting for NIH-funded vertebrate animal and human studies. The ORWH leads collaborations across the NIH to implement this policy and develop research programs such as Building Interdisciplinary Research Careers in Women's Health (BIRCWH), an initiative that aims to increase the number and skills of investigators who conduct research on sex and gender influences on health and disease. The Specialized Centers of Research Excellence (SCORE), another signature ORWH program, is designed to expedite the development and application of new knowledge to human diseases that affect women, to learn more about the etiology of these diseases, and to foster improved approaches to treatment and/or prevention. The ORWH needs adequate funding to continue these initiatives and to support scientists across the country who are conducting groundbreaking research on sex differences.

### **National Institute on Minority Health and Health Disparities (NIMHD)**

The NIMHD serves as the leader on scientific research initiatives dedicated to improving minority health and reducing health disparities — differences in the incidence and outcome of health conditions among specific populations defined by race or ethnicity, sex and gender, disability status, geographic location, or other sociodemographic classifications. The NIMHD invests in critical research on minority health and health disparities. Its work informs practice and policy to increase the scientific community's focus on equally important non-biological factors such as socioeconomic, discrimination, culture, and environment in relation to health disparities.

### **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

The CDC's Division of Reproductive Health (DRH) and its goals of improving women's health from menarche to menopause; improving pregnancy health and care; and improving fetal, newborn, and infant health are areas of fundamental importance to women and their families. The DRH's work to address issues of chronic disease among women of reproductive age and its data collection efforts related to pregnancy outcomes, maternal mortality, and medications in pregnancy must continue. Funding for maternal mortality review committees (MMRCs), perinatal quality collaboratives (PQCs), and other initiatives that investigate and transparently report on maternal mortality causes while reducing health disparities are essential in tackling our nation's rising maternal mortality rates.

Additionally, the CDC's work will be vital to continued disease monitoring and prevention during the novel coronavirus outbreak. Studying sex and gender differences in COVID-19 infection rates and outcomes will help us to figure out why the virus is affecting men more severely and to understand how we can better improve our responses to future pandemics. Increasing CDC funding for pandemic response will improve the agency's ability to collect reliable, consistent data about COVID-19, including sex and gender differences in deaths, symptoms, risk factors, and virus exposure.

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**HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)**

The work of HRSA is crucial to women's health. HRSA's initiatives reduce infant mortality and improve maternal health and wellbeing through its support of pregnant women, mothers, and their families. The Title V Maternal and Child Health (MCH) Block Grant is specifically tailored to address the needs of pregnant women and their families by providing access to comprehensive prenatal and postnatal care to women — especially low-income and at-risk pregnant women. HRSA support saves federal and state governments money by ensuring delivery of preventive services to avoid more costly chronic conditions later in life.

**Agency for Healthcare Research and Quality (AHRQ)**

AHRQ ensures that research is translated from bench to bedside through comprehensive implementation in the everyday practice of medicine. AHRQ is the only federal agency that funds research on “real-life” patients — including women with comorbidities and co-existing conditions and high-risk pregnant women. Approximately 38% of women have a least one diagnosed chronic disease, as compared to 30% of men, making this a topic of particular relevance to women's health, as individuals with complex comorbidities are typically excluded from research studies. Budget cuts in recent years have led to termination of various disease programs and portfolios, limiting the impact of AHRQ's important work. Increasing AHRQ's funding will lead to better care for women and for all Americans.

**CONCLUSION**

In conclusion, I would like to thank the Chair, Ranking Member, and the Committee for their support for medical and health services research and their commitment to the health of the nation. Thank you in advance for consideration of this HHS FY2021 funding request and the rationale behind it. If you have questions, please contact Melissa Laitner, PhD, MPH, Director of Science Policy, at [melissa@swhr.org](mailto:melissa@swhr.org).